

Supported Parenting Briefing Paper June 8, 2000

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Introduction

No single system takes responsibility for supporting families headed by parents with disabilities. Families headed by parents with cognitive disabilities are becoming more visible in our communities and are becoming increasingly noticed within several service systems. Child protective services, health care, welfare and work programs, developmental disability services for families and children, developmental disability services for adults, family violence and child abuse agencies generally recognize that parents with disabilities and their children are both under-served and inadequately served in these systems. However, in state government and in most Wisconsin communities, there is no single system stepping forward to take primary responsibility for mobilizing and coordinating supports tailored specifically to the needs of parents with cognitive disabilities. Gradually, over the last 10 years, a few Wisconsin communities have begun to develop the capacity to support these families. This paper focuses on parents with cognitive disabilities and their families. Parents with other types of disabilities such as physical disabilities or mental illness require other support modalities than those of parents whose need for support results from their cognitive limitations.

Supported Parenting

Supported parenting is the term used to describe supports adapted to the special needs of parents with cognitive disabilities. There is no system of supported parenting nor is there a designated funding source. Supported parenting is as much a philosophy or attitude as it is a specialized program. Support is based on an understanding and acceptance of the characteristics, life circumstances, needs, and desires of persons with disabilities.

Supported parenting can be found within agencies providing services to a wide range of individuals and families and it can be found in programs with the single specialty of serving families headed by parents with disabilities. When specialized support for parents with disabilities is available it can come from a variety of systems.

Parents with Cognitive Disabilities

What do we know about parents with disabilities?

Given the chance, most parents with cognitive disabilities successfully establish loving bonds with their children but many have difficulty with the day-to-day demands of caring for their children. While a parent with cognitive disabilities has unique combinations of strengths and support needs, many seem to share some common problems. Parents with cognitive disabilities tend to have some difficulty retaining and correctly applying the

information and skills needed for adequate parenting. Many lack social and play skills and have a hard time managing money. For parents who have difficulty in communication and social relationships, the effect is seen not only in the parent-child relationships but also in the family's ability to relate within the community, including the service systems that become involved in their lives.

How do the children fare?

Interviews of adults who grew up in households headed by parents with cognitive disabilities reveal that while their parents' disabilities created some difficulties and embarrassment, on the whole, they loved their parents, felt loyal to their families, and grew up learning values and lessons that sustain them as adults (Tim and Wendy Booth, *Growing up with parents with learning difficulties*, New York, Routledge, 1998). Children of parents who have cognitive disabilities have a somewhat greater chance of developing disabilities. But with supportive interventions available to the family, the chance of developing disabilities decreases. Child neglect is a greater risk for parents with cognitive disabilities than the risk of abuse. When neglect occurs, it is typically not purposeful neglect but the result of actions and judgments that reflect inadequate training and support. Parents with adequate and appropriate supports are able to learn and apply knowledge and skills when support is matched to the parents' learning style. When abuse occurs, it is usually not attributable to the parent's cognitive disability but to other attributes of the parent or to household members other than the parent with cognitive disabilities.

Predictors for successful parenting

Parents known for their disabilities also have abilities that can be enhanced by our support services. It is important to separate personality from disability, to acknowledge that cognitive disability is only about how people learn. Rarely is it the most significant factor in deciding whether someone can parent adequately. Attending to the well being and health of families headed by parents with disabilities requires identifying and overcoming the barriers to support.

Among parents with cognitive disabilities, those who have reading skills do better at parenting than those who do not read. Parents free of serious medical, psychiatric or substance abuse conditions are more successful at parenting. Parents with cognitive disabilities who have experienced sexual abuse or who have an abusive partner have more difficulty parenting. Parents, themselves, identify sufficient and appropriate support as an important key to successful parenting.

Characteristics of current systems

Developmental disabilities service system

Parents with disabilities often have difficulty securing resources and negotiating the complexities of the human service system. Agencies with the most expertise in developmental disabilities are the least likely to be involved with families. Typically, developmental disabilities services are set up to serve single adults or families in which the family member with the disability is a child. Residential and vocational support

programs for adults with disabilities are not usually equipped to support parenting roles. Family support programs may have expertise in child disability but staff may not have the skills to adapt support to be useful to parents with disabilities.

Child protective services

Families headed by parents with cognitive disabilities may be referred to county child protective services when there are concerns about neglect or abuse. Protective services can be voluntary but, due to budget constraints, are often available only on a court-ordered basis. For the court to order services, explicit risk of harm to the child must be evident. Protective services ordinarily are crisis-oriented, short-term interventions designed to correct a particular problem. Most protective service agencies are not organized to provide help to parents who will need support over the long term. Caseloads are large and workers are expected to have cases turn over rapidly. Protective service workers can find themselves in the contradictory role of trying to establish a helping relationship with the family while at the same time gathering evidence of parental inadequacy and influencing whether the family remains intact.

Health care

Families headed by parents with cognitive disabilities may have contact with pediatric health care providers and local public health nursing agencies, especially around the time of the birth of a child and during the infancy and early childhood years. Interventions often rely on the parent's ability to read and to apply instructions in various circumstances. There is a large variation in the quantity and intensity of pediatric care and public health nursing available to families. Common characteristics include the expectation that services will be specific and brief.

Welfare

Welfare and work programs exclude parents with disabilities if they are eligible for Supplemental Security Income (SSI). Parents with disabilities who are participating in welfare and work programs can be sanctioned with loss of income for missing appointments or failing to complete tasks. The singular focus on employment may have the unintended effect of preempting the parent's availability for involvement in parenting programs.

Schools

Schools may assume parents of students will have the ability to respond to written information sent home with the child. When parents can't read or respond to school expectations, or when students come to school unprepared to learn because of a disorganized home environment, school personnel do not ordinarily have the capacity to respond in ways that are supportive or helpful to the parent with cognitive disabilities.

Many schools have special programs for students who become parents while still enrolled in school. Rarely are these available or adapted to the learning needs of special education students who become parents.

Barriers to community resources

Parents with disabilities find similar barriers to other community resources for parents and families, such as family resource centers, child abuse prevention programs, domestic abuse shelters, and law enforcement agencies. In those circumstances when a family overcomes the barriers to entry into a community service or program, the family's needs may result in a cascade of referrals and involvement with an overwhelming number of programs, agencies, and workers. Lacking coordination of these multiple involvements, providers may experience confusion about their various roles and boundaries. Parents may have difficulty understanding the deluge of often contradictory information, advice, and expectations, and may cease to participate. Parents with cognitive disabilities are sometimes interpreted as noncompliant or overly dependent while their cognitive limitations are not always acknowledged or understood.

Qualities of effective support

Supporting through teaching

Successful teaching of parents with cognitive disabilities requires not only an understanding and acceptance of the characteristics of their disabilities and life circumstances, but also knowledge of appropriate techniques for their successful learning. Mark Sweet (in *Discovering the Parent's Language of Learning: an Educational Approach to Supporting Parents with Cognitive Disabilities*, 2nd edition. Madison, Wisconsin Council on Developmental Disabilities, 2000) recommends putting together an instructional strategy that accounts for the parent's individual learning style, the parent's current knowledge, behavior, attitudes, beliefs, values, available support systems, and available resources.

Supporting recovery from abuse

Cognitive disability brings its own set of obstacles to successful parenting, but for most families, the parent's cognitive disability is not the primary reason for failure. Research shows that the mental health of the mother can be a critical factor. Research on sexual abuse and people with cognitive disabilities indicates a disturbingly high percentage of people with disabilities experience sexual abuse (over 80% in studies quoted by Dick Sobsey in *Violence and Abuse in the Lives of People with Disabilities*, Baltimore, Brookes, 1994, and by Roy Froemming in *At Greater Risk: Legal Issues in Sexual Abuse of Adults with Developmental Disabilities*, Madison, Wisconsin Council on Developmental Disabilities, 1991). Virtually all the mothers interviewed in a Wisconsin Council on Developmental Disabilities supported parenting learning project described themselves as survivors of past or current sexual and physical abuse (Hoffman and Mandeville, *Amelioration of Health Problems of Children with Parents with Mental Retardation*, Madison, WCDD, 1991). This is of particular concern because of the effects of sexual abuse on parents' own self-esteem and their capacity to develop healthy relationships with family members.

Reevaluating interventions

One of the most challenging aspects in supporting families headed by parents with disabilities is encountering the gray line that separates parental care that may be less than optimal but “good enough” from parental behavior that is detrimental to the child (John Franz in *Facing the challenge: The children’s code and families headed by parents with mental retardation*, Madison, Wisconsin Council on Developmental Disabilities, 1990).

A trend can be discerned from recent trial court cases and federal and state legislative initiatives that suggests a shift away from the family preservation policies that in many ways were consistent with the principles of supported parenting. Instead of mobilizing support for families to keep them intact, agency practices and court rulings communicate impatience with long term interventions and favor the acceleration of the process that results in terminating parental rights. Support providers are brought into this debate when they are called upon to make judgments about a family's prospects. Their opinions influence whether or not the family stays intact. Only compelling evidence of harm should trigger termination of parental rights. Permanency planning policy is premised on the idea that direct, time-limited interventions will lead to prompt answers regarding whether the family stays intact or a child is freed for another permanent option such as adoption.

The system’s responsibility is protection and support, not choosing “better parents” for children

It is understandable that well-meaning individuals who care for children would look favorably upon placing them in environments perceived to be more promising. However, the system’s prerogative is not to choose “better parents” for children, but only to protect them from life threatening ones. Therefore, the wisest and most ethical course seems to be to diligently devote system resources to providing supports and services to the natural parents to increase their capabilities, and to establish a natural support system that will sustain them.

What Parents Want in Support Services

Listen to parents

A parent's disability, in itself, does not necessarily determine whether a parent will be a “good enough” parent. While the individual characteristics of the parent are important, the characteristics of the supports available have a lot of influence over whether parents will succeed. Parents with cognitive disabilities have identified characteristics of both effective support and inadequate support. These insights from parents were obtained from interviews with Wisconsin parents (Dolores Liamba, *Cultivating Competence: Directory and Resource Guide on Supported Parenting*, 2nd edition, Madison, Wisconsin Council on Developmental Disabilities, 2000) and adapted from the reports of two researchers from Great Britain, Wendy and Tim Booth (in *Advocacy for Parents with Learning Difficulties*, Brighton, England, Pavilion Publishing, 1998).

Here is a sample of lessons learned from parents who rely on supported parenting services:

- Build a trusting, mutual relationship with parents.
- Acknowledge the parent's role as head of household.
- Appreciate the love between parent and child, despite the problems.
- Offer sustained, practical support directed toward building the parent's own skills and confidence.
- Match the family with personnel who have a genuine liking for the family.
- Recognize the emotional needs of parents; build parents' self-esteem and confidence.
- Mobilize community supports; connect with other agencies involved with a family.
- Integrate formal services with support and involvement of extended family, neighbors and friends.
- Turn to the parent to determine the most effective direction for support.
- Develop an advocacy role representing the family to the service system rather than present oneself to the family as an agent of the system.

Parents' list of characteristics of unsatisfactory support

Parents in Wisconsin and England also identified a number of practices that are not helpful and, in fact, create an additional layer of stress in lives already burdened with difficulties. Parents who are veterans of various service systems have said their families do NOT benefit from involvement when workers and agencies:

- Offer an inflexible, "one-size fits all" approach that doesn't take individual differences into account.
- Focus on deficits; overlooking parents' capacities.
- Employ a judging, skeptical and punitive approach.
- Use threats of removing the child to coerce compliance.
- Conclude that parents are deficient in situations when really it is the service approach that is inadequate.
- React to crises but failing to anticipate and prevent problems.

- Fail to sustain continuity in the support relationship with the family and failing to coordinate and communicate with other agencies involved with a family.
- Diminish the importance of family relationships and friends.
- Assign workers who lack personal experience of parenting.

Supported Parenting Programs in Wisconsin

Several Wisconsin communities have mobilized a variety of resources and funding sources to create flexible support options for parents with disabilities and their families. The programs listed here have established specialized supported parenting services. A growing number of other agencies are beginning to incorporate supported parenting principles and practices into the services they provide to a more generalized population so that they can tailor their services to meet the needs of parents with cognitive disabilities.

The supported parenting programs listed here provide their direct support services to local families. Some have waiting lists. Some training events and technical assistance activities are available occasionally in statewide or regional conferences and workshops. These are co-sponsored by the University of Wisconsin Health Promotion Project, Department of Professional and Applied Studies, Division of Continuing Studies (608/265-2233) and the Wisconsin Council on Developmental Disabilities (608/266-7851).

Supported Parenting Program
Developmental Disabilities Counseling
3311 Prairie Avenue
Beloit WI 53511
608/365-8787

Parents and Children Together Program
Exchange Center
2120 Fordem Avenue
Madison WI 53704
608/ 241-3434

Neighbors Network
Jackson County HSD
PO Box 457, 420 Highway 54 West
Black River Falls WI 54615
715/284-4301

Family Education and Resource Center
540 North Eighth Street
Manitowoc WI 54220
920/682-1742

Healthy Families Program
Family Services
131 South Madison Street
Green Bay WI 54301
920/436-4374

Community Living Program
Milwaukee Center for Independence
1339 North Milwaukee Street
Milwaukee WI 53202
414/ 272-9277

Positive Parenting Program
Brown County ARC
PO Box 12770
Green Bay WI 54307
920/498-2599

Supported Living Project
Catholic Charities Waukesha
741 North Grand Avenue
Waukesha WI 53186
414/547-2463